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ABSTRACT

This report describes the Federal commitment to improve early intervention services that enhance development and minimize the later dependence of infants and toddlers with handicaps. It presents the results of a joint study, completed by the Department of Education (DoE) and the Department of Health and Human Services (DHHS), of early intervention services and the coordination efforts to achieve the goals of the Handicapped Infants and Toddlers Program. The report examines federal funding sources and services that provide financial assistance to states to develop and implement programs, identifies gaps in early intervention services, and describes joint activities under way among federal agencies supporting early intervention programs and future actions planned to facilitate the coordination of services. An appendix offers descriptions of 16 programs that authorize or provide early intervention services, many of them targeted to the poor or to individuals with low incomes. Other appendices list appropriations of DoE and DHHS programs contributing to early intervention for fiscal years 1987 and 1988 and reprint a memorandum of agreement for the Federal Interagency Coordinating Committee. (Four references) (JDD)

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MEETING THE NEEDS OF INFANTS AND TODDLERS WITH HANDICAPS

FEDERAL RESOURCES, SERVICES, AND COORDINATION EFFORTS IN THE DEPARTMENTS OF EDUCATION AND HEALTH AND HUMAN SERVICES

A Report to the Congress

by

The Department of Education and the Department of Health and Human Services

January 1989

EC 300 589

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F O R E W O R D

Children and the families that support them are the future of our nation. We must assure that the smallest and most vulnerable of our children, those with special needs, have the fullest opportunity to develop the capacity to participate in all aspects of American society. The Handicapped Infants and Toddlers Program established in the Education of the Handicapped Act Amendments of 1986 focuses national attention on the needs of families with infants and toddlers who experience or are at risk of having handicaps. This legislation provides impetus and assistance to coordinate Federal, State and local efforts on behalf of these young children and their families. This coordination is a part of a broader system that has been put in place to assist individuals with disabilities from birth through adulthood.

This report outlines an interagency agenda to provide national leadership to improve early intervention services that enhance development and minimize the later dependence of infants and toddlers with handicaps. The report describes the Federal commitment to these services and the activities to achieve the goals of the Handicapped Infants and Toddlers program.

Lauro F. Cavazos
Secretary of Education

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Secretary of Health
and
Human Services

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CHAPTER 1

INTRODUCTION

This is a report about infants and toddlers with handicaps and their families. In 1986, the Congress enacted a national program to expand and improve early intervention services through the Education of the Handicapped Act Amendments (Public Law 99-457). The Handicapped Infants and Toddlers Program created by this legislation helps States provide family-centered support to infants and toddlers through individually designed early intervention services. Early intervention services have been a part of Federal efforts to assist individuals in need for many years. The Handicapped Infants and Toddlers Program challenges the nation to improve, expand, and coordinate those services so that the policy goal of statewide, comprehensive and coordinated programs of early intervention services for all infants and toddlers with handicaps and their families can be achieved.

The Handicapped Infants and Toddlers Program is designed for children from birth through two years of age who need early intervention services because they are experiencing developmental delays or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. States have the option to include services for additional infants who are at risk of having substantial developmental delays. Early intervention services under this program must meet the folowing criteria: (1) be provided under public supervision; (2) be provided at no cost, except where Federal or State law provides for payments by families; (3) be designed to meet the individual's developmental needs; (4) meet the standards of the State; (5) be provided by qualified personnel; and (6) be provided in conformity with an Individualized Family Service Plan.

Early intervention services include:

- Family training, counseling, and home visits
- Special instruction
- Speech pathology and audiology
- Occupational and physical therapy

- Psychological services
- Case management services
- Medical services for diagnosis and evaluation
- Health services necessary for the child to benefit from other early intervention services
- Other services that support development in accordance with the definition of early intervention

Congress anticipated that these services would enhance the development of infants and toddlers with handicaps, reduce the need for special education and related services after these infants and toddlers reach school age, maximize the likelihood that individuals with handicaps ultimately will live productive lives in the community, enhance the capacity of families to meet the needs of members who have handicaps, and reduce family stress.

As one step in implementation of the Handicapped Infants and Toddlers Program, the Congress mandated a study of the Federal resources available for early intervention services and a report of the coordination efforts to achieve the goals of the program. Specifically, the statute requires that:

> "The Secretary of Education and the Secretary of Health and Human Services shall conduct a joint study of Federal funding sources and services for early intervention programs currently available and shall jointly act to facilitate interagency coordination of Federal resources for such programs and to ensure that funding available to handicapped infants, toddlers, children, and youth from Federal programs, other than programs under the Education of the Handicapped Act, is not being withdrawn or reduced.
>
> "Not later than 18 months after the date of the enactment of this Act, the Secretary of Education and the Secretary of Health and Human Services shall submit a joint report to the Congress describing the findings of the study conducted under paragraph (1) and describing the joint action taken under that paragraph."

This document reports the results of this joint study of services by the Departments of Education and Health and Human Services. The study addresses the two separate, but related, requirements in the congressional mandate: First, it identifies and describes the Federal funding sources and services in the two Departments that assist in the provision of early intervention services, based on their statutes as of December 31, 1987. Second, the study describes the joint actions among agencies in the two Departments to facilitate interagency coordination of services and resources for early intervention programs.

In order to design and oversee the joint study, the two Departments created an interagency work group consisting of representatives from agencies with major responsibilities affecting infants and toddlers with handicaps and their families. (See Appendix A for the membership of the work group.) The work of this interagency work group was supplemented by a consultant service contract with COSMOS Corporation of Washington, D. C. The contractor assisted the work group in documenting Federal programs and evaluating their effects through six State and twelve local agency site visits.

To address the first stated purpose of the study -- identification of Federal funding sources and services -- the work group evaluated and compiled information from the following sources:

- Joint Study of Services and Funding for Handicapped Infants and Toddlers, Ages 0 Through 2 Years (Schafft, Erlanger, Rudolph, Yin and Scott, 1987). This document was prepared by COSMOS Corporation as a part of its contract to assist the work group with the joint study. The report details the results of structured interviews with key personnel from Federal agencies identified as providing services or financing for the early intervention program described in Public Law 99-457. Data were collected describing the programs, service recipients, and funding levels. The report provides results of interviews with State and local officials to examine how Federal funds actually flow to and are used by early intervention programs. Purposive selection of six States and twelve local service agencies provided information about early intervention services and resources in a representative cross-section of administrative, service delivery, demographic, and financial circumstances.

- A Survey of Current Status on Implementation of Infants and Toddlers Legislation (Gallagher, Harbin, Thomas, Wenger, and Clifford, 1988). This report, prepared by the University of North Carolina's Early Childhood Research Institute on Policy, was funded in 1987 by the Office of Special Education Programs and describes activities and experiences of States in initial efforts to meet the coordination mandate of the Handicapped Infants and Toddlers Program.

- A Report on Year 1 Activities Under Part H--The Handicapped Infants and Toddlers Program (NASDSE, 1988). Prepared by the National Association of State Directors of Special Education, this report describes the activities reported by States in the first year of implementation of the Handicapped Infants and Toddlers Program.

- The National Early Childhood Technical Assistance System: National Technical Assistance Plan (Trohanis, Kahn, Hurth, Danaher, Black, and Heekin, 1988). This report details the technical assistance needs identified by States for the first year of implementation of the Handicapped Infants and Toddlers Program and serves as an index of the current status of program implementation efforts.

The work group also assumed primary responsibility for the second requirement of the joint study -- the identification of the joint actions of agencies in the two Departments to facilitate interagency coordination of Federal resources and programs. The work group identified joint activities that were already under way among Federal agencies supporting early intervention programs and several future actions that are planned to facilitate the coordination of services. Chapter 3 reports the results of this effort.

C H A P T E R 2

FEDERAL FUNDING SOURCES AND SERVICES FOR EARLY INTERVENTION

This chapter provides the results of the study of Federal funding sources and services in the Departments of Education and Health and Human Services that can support the congressional goal of providing financial assistance to States to develop and implement programs of early intervention services for all infants and toddlers with handicaps and their families. The chapter is organized around two fundamental questions about coordination of payments for early intervention. The first question addresses what Federal programs and services provide early intervention services and resources. The second question addresses whether these programs now result in the statewide, comprehensive, coordinated, multidisciplinary, interagency services envisioned by the Congress.

What Federal Programs Provide Early Intervention and Services?

Interagency coordination of funds and services for early intervention can occur only when accurate information is available about the programs providing these funds. Review and synthesis of the reports referenced in Chapter 1 by the interagency work group helped to identify the programs in both Departments that could provide funding for early intervention services as a part of broad legislative authorities. Analyses of the legislation for each program assisted the work group in the final identification of those Federal funding sources and services that can support early intervention. The results of the joint study of funding sources are presented in this section.

Sixteen Federal programs provide ongoing funding that States can use to support early intervention.

The Departments of Education and Health and Human Services administer 16 programs that have significant potential to contribute resources toward the successful implementation of a statewide sys-

tem of comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services. These programs are characterized by:

- Legislative authority that includes early intervention services among permissible uses of funds and types of services to be provided. If discretion exists in the legislative authorities, it has been assigned to the States rather than to the Federal government.

- Legislative authority that either directly authorizes one or more early intervention services, as defined in the Handicapped Infants and Toddlers Program, or that allows one or more of these services through broad statutory language.

The 16 programs identified in the study are described in Appendix B. They are:

- **Handicapped Infants and Toddlers Program**, authorized by the Education of the Handicapped Act (Handicapped Infants and Toddlers Program),

- **Chapter 1 Handicapped Program**, authorized by the Education Consolidation and Improvement Act (Chapter 1),

- **Assistance for Education of All Handicapped Children**, authorized by the Education of the Handicapped Act (Part B),

- **Head Start Program**, authorized by the Head Start Act (Head Start),

- **Medicaid** programs, authorized by the Social Security Act (Medicaid),

- **Maternal and Child Health Block Grants**, authorized by the Social Security Act (MCH Block Grant),

- **Child Welfare Services Program**, authorized by the Social Security Act (Child Welfare),

- **Developmental Disabilities Basic State Grants Program**, authorized by the Developmental Disabilities Assistance and Bill of Rights Act (ADD Basic State Grants),

- **Alcohol, Drug Abuse and Mental Health Block Grant Program**, authorized by the Public Health Service Act (Mental Health Block Grant),

- **Community Health Service Program**, authorized by the Public Health Service Act (Community Health),

- **Indian Health Service Program**, authorized by the Indian Health Care Improvement Act (Indian Health),

- **Migrant Health Services Program**, authorized by the Public Health Service Act (Migrant Health),

- **Preventative Health and Health Services Block Grant**, authorized by the Public Health Service Act (Health Block Grant),

- **Health Care for the Homeless Program**, authorized by the Homeless Assistance Act (Health for Homeless),

- **Social Services Block Grant**, authorized by the Social Security Act (Social Services Block Grant).

These programs reflect legislative efforts to address a variety of special population needs, including the needs of persons who are handicapped, developmentally disabled, severely emotionally disturbed, deaf-blind, medically needy, substance abusers, poor, American Indian, migrants, and homeless. These programs reflect legislation to meet such needs as social services, nutrition, mental health, independent living, health and preventive health services, rehabilitation, education, and early intervention.

The chart on page 9 demonstrates how these 16 programs are dispersed throughout the two Departments. The responsibility for their administration is shared by four principal operating components.

As is apparent in the descriptions provided in Appendix B, these programs vary widely in their eligibility criteria and the discretion recipients have in providing early intervention services. Program eligibility criteria differ by age groupings such as birth through 2, birth through 5, birth through 20, or all ages. Some programs have income eligibility criteria; others are designed for specific groups such as migrant families. In other instances, they are designed for

at-risk populations such as the medically under-served. Some of the programs are designed for the individual, others for the family, and others to develop system capacity in States and communities.

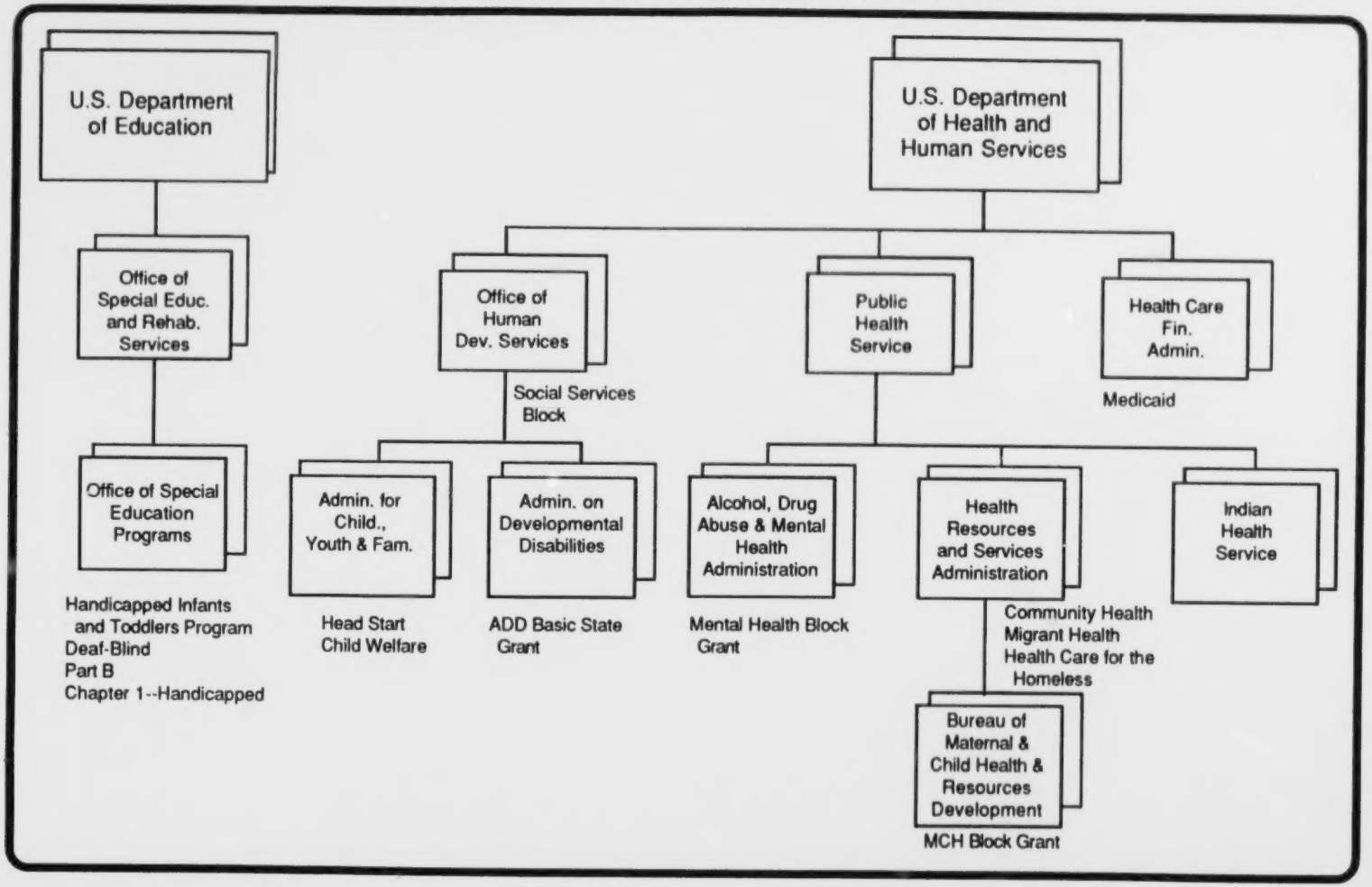
The 16 programs differ in the nature of discretion provided States in selecting among competing service needs such as developmental, educational, physical and mental health needs or welfare and employment needs. They also differ in the age groups eligible to receive services. For example, the Developmental Disabilities Basic State Grant program provides grants to States to fund services for persons with developmental disabilities. Eligibility for these funds is restricted to those individuals with severe and chronic disabilities that have manifested themselves before the individual reaches age 22. Infants and toddlers with handicaps are included in this broad category of eligibility. However, whether these Federal funds are used to provide early intervention services is dependent on whether a State selects those priorities that can provide these services and then actually serves infants and toddlers. In the Chapter 1, Part B, and Deaf-Blind programs, infants and toddlers with handicaps are subsumed under a larger age span of eligibility. Furthermore, statutory authority can restrict the range and types of early intervention services potentially available under many of these programs.

The 16 Federal programs reflect not only a broad array of eligibility criteria and varying degrees of State discretion in establishing and selecting service priorities and populations served but also in funding approaches. These approaches include: single-focus grants, State formula grant programs such as the Handicapped Infants and Toddlers Program; multi-purpose block grants to States such as the MCH Block Grant; and entitlement programs such as Medicaid, where States receive payments for services provided.

The structure of most of these programs requires that early intervention compete for resources with other services and populations.

The 16 programs provide the foundation of Federal support for early intervention services. They indicate a broad Federal commitment to the provision of resources and services consistent with the early intervention goals of the Handicapped Infants and Toddlers Program. However, only one of these Federal programs, the Handicapped Infants and Toddlers Program, targets funds specifically for early intervention. In the remaining 15 programs, early intervention services are one of many potential uses of the Federal funds. Each

ORGANIZATIONAL LOCATION OF PROGRAMS PROVIDING AT LEAST ONE EARLY INTERVENTION SERVICE


U.S. Department of Education
Office of Special Educ. and Rehab. Services
Office of Special Education Programs
Handicapped Infants and Toddlers Program
Deaf-Blind
Part B
Chapter 1--Handicapped
U.S. Department of Health and Human Services
Office of Human Dev. Services
Social Services Block
Admin. for Child., Youth & Fam.
Head Start
Child Welfare
Admin. on Developmental Disabilities
ADD Basic State Grant
Public Health Service
Alcohol, Drug Abuse & Mental Health Administration
Mental Health Block Grant
Health Resources and Services Administration
Community Health
Migrant Health
Health Care for the Homeless
Bureau of Maternal & Child Health & Resources Development
MCH Block Grant
Health Care Fin. Admin.
Medicaid
Indian Health Service

of these programs provides States and communities with discretion in establishing priorities for the types of services or the age groups to be targeted with Federal funds. The result of leaving discretion for establishing priorities to States and communities is to place infants and toddlers with handicaps and their families in competition with other groups for the funds needed for early intervention.

The extent of this competition differs from program to program. seven of the 16 Federal programs are specifically targeted for individuals with handicaps. In these programs, early intervention competes with services for other age groups. For example, Chapter 1 provides funds to States to provide special education and related services to handicapped children from birth through age 20 in State-operated or supported programs. Whether these Federal funds are used to provide early intervention services is at the discretion of the States. Likewise, the use of Part B and Deaf-Blind program funds is dependent on each State's discretion. In both of these programs, infants and toddlers with handicaps are subsumed under a larger age span of eligibility, and program limitations restrict the range of early intervention services potentially available with these funds.

The other nine programs, while not specifically targeting individuals with handicaps or disabilities, do not exclude them from participation. For example, Medicaid services for the categorically needy include inpatient and outpatient services, physicians' and dentists' services, and early and periodic screening, diagnosis, and treatment (EPSDT) for children 21 years of age and under. EPSDT provides comprehensive and preventative health services to screen for physical and mental disabilities and to provide treatment for conditions found through the diagnostic services. At a State's option, medically needy, low-income persons who meet the categorical but not the financial criteria for regular Medicaid eligibility can receive medical services such as those described above. If a State elects to serve the medically needy, medical assistance must be provided to children up to 18 years of age who satisfy the cash assistance criteria for Aid to Families with Dependent Children (AFDC) or for Supplemental Security Income (SSI).

Additional programs can be used by Federal agencies to assist in the development of quality early intervention services.

Similar competition for resources is apparent in the MCH Block Grant, which provides mothers and children, especially those with

low incomes or limited access to health services, with quality health services to reduce infant mortality and prevent handicapping conditions. The grant promotes the health of those mothers and children through primary pediatric and prenatal care. Several other health care programs in the Public Health Service target special population groups such as American Indians, migrants and homeless persons and provide many of the same services described above. In each of these programs, early intervention services compete for resources with other health service needs of the identified population.

A second group of potential Federal funding sources for early intervention are those programs with legislative authorities broad enough to include projects designed to improve the quality of early intervention. In contrast to the 16 programs identified above, these are not meant to provide funding for direct services. Rather, they provide funding for research, demonstration, technical assistance, information exchange, and training projects that can improve the quality of early intervention programs and services. Typically, these funds are available for projects of limited duration, and decisions about what types of projects within Federal priorities will be funded is left to the discretion of Federal program offices. These discretionary funds can provide the information, designs, and training needed to advance the implementation of statewide comprehensive early intervention systems. Most of the discretionary programs are not focused solely on handicapped children from birth through two years, but can include this population (e.g., the Handicapped Children's Early Education Program). The discretionary programs are broad in scope, as is evidenced in their federally established priorities. While these programs are not the subject of the joint study mandated by the Congress, their contribution is significant and several examples have been included.

- **The Handicapped Children's Early Education Program (HCEEP)**, administered by the Department of Education, Office of Special Education Programs, funds approximately 120 projects annually to develop, evaluate and disseminate new knowledge regarding educational or developmental intervention strategies for children with handicaps, birth through age eight, and their families; state-of-the-art information regarding intervention strategies is disseminated to State agencies and local intervention programs.

- **The Division of Personnel Preparation**, administered by the Department of Education, Office of Special Education Programs, annually funds approximately 40 personnel prepara-

tion grants which address the need for preservice preparation of personnel who will work with infants and toddlers with handicaps and their families.

- **The National Institute on Disability and Rehabilitation Research**, administered by the Department of Education, annually funds a research and training center on children, as well as several projects designed to develop new and innovative strategies to serve young children with handicaps and their families.

- **Special Projects of Regional and National Significance (SPRANS)**, managed by the Public Health Service Bureau of Maternal and Child Health Resources and Development, provides funds for projects engaged in research, training, genetic testing, counseling, and development of new information. These projects focus on children with chronic illness or disabilities, including infants and toddlers.

- **The University Affiliated Programs**, of which 35 are administered by the Administration on Developmental Disabilities in the Office of Human Development Services, and 21 by the Bureau of Maternal and Child Health Resources and Development, receive funds to support the training of personnel to address the needs of persons with developmental disabilities in areas of emerging national significance, including early intervention.

- **The Child and Adolescent Service Systems Program (CASSP)**, managed by the National Institute of Mental Health, funds projects designed to promote the development of more effective coordination of services for children who exhibit severe emotional disturbance.

In addition, there are many other discretionary programs that fund projects to provide information to parents and technical assistance to States, and to develop in-service training material. These programs help incorporate the most up-to-date design of early intervention programs and delivery of early intervention services. Furthermore, these programs provide resources for the discovery of new knowledge and the development of new applications for improving early intervention services.

Do These Federal Funding Sources and Services Result in Comprehensive Early Intervention Systems?

The 16 programs discussed in the previous section could provide significant resources for early intervention services. However, given the diverse human, social and political objectives underlying the various statutes authorizing these programs, it is important to recognize that the 16 programs were never designed to be component parts of statewide, comprehensive early intervention systems.

Instead, as discussed in the preceding section, the programs were designed to address a wide variety of special population and human service needs. The variety of goals both across and within programs confirms the recognition of the congressional legislative hearings that comprehensive statewide early intervention services are not yet available.

Gaps exist in the early intervention services currently available.

Recipient, service, delivery system, and geographic gaps in early intervention services were identified in the Schafft, et al. (1987) study of 6 States and 12 community service providers. Recipient gaps exist when early intervention services are available to some, but not all, infants and toddlers in need of services. Recipient gaps identified in the Schafft, et al. study included: infants and toddlers from minority groups, homeless families, families experiencing disorganization, and infants and toddlers at risk for handicaps.

The recipient gaps that have been identified probably represent very conservative estimates, since they are typically based on counts of children already identified and waiting for services. There is a real possibility that the children who have been identified represent only a fraction of those needing services. The limitations of existing child find programs for infants and toddlers and the efforts now under way to improve the effectiveness of such programs (Trohanis, et al. 1988; NASDSE, 1988) make it likely that current estimates are based on under-identification of those needing services. Under-identification

of infants and toddlers who need intervention services may be the result of several different factors. For example, it may reflect inadequate interagency referral procedures, eligibility criteria that differ across agencies conducting child find programs, or hesitation by some professionals to refer some young children for services. Further, service providers may be hesitant to implement rigorous child find procedures when early intervention services are not available to meet such needs.

Service gaps exist when some, but not all, needed early intervention services are available. For example, in the Schafft, et al. (1987) study, State agency staff, local community service providers, and parents reported service gaps in the areas of pediatric speech and audiology, pediatric physical therapy, and respite care. Personnel shortages accounted for most of the service gaps.

Delivery system gaps exist when services are available only through agencies with limited capacity to meet all early intervention service needs. For example, the lack in some programs of specialized personnel, such as physical, occupational and language therapists, and nurses, was cited by Schafft, et al. (1987) as a reason for the lack of early intervention services. Another delivery system gap resulted when early intervention services were available only in a single setting, such as a hospital. In this instance, families requiring home-based services were unable to obtain needed assistance.

State and local coordination efforts are not yet adequate to ensure comprehensive services.

Finally, geographic gaps in early intervention services were described in rural areas not only because of a lack of trained personnel but also because public transportation to regional hospitals or center-based programs was unavailable.

A survey of the State coordinators of the Handicapped Infants and Toddlers Program conducted by Gallagher, et al. (1988) indicates that States, on the average, use funds from 11 Federal programs to provide early intervention services. However, only two-thirds of the coordinators reported any effort to coordinate all potential Federal resources. The survey indicated that where coordination efforts do occur, they are, in general, limited to three or four sources of funds, typically health and education funds. Schafft, et al. (1987) found that States expect extreme difficulties in achieving the complex coordination required by the Handicapped Infants and Toddlers

Program. For example, coordination difficulties are likely to result from differences in the eligibility criteria of the Federal programs, differences in their funding approaches, discretion in setting priorities for funding, and discretion in determining the target of assistance (e.g., the service provider, family or individual).

Schafft, et al. (1987) reported that some coordination exists at the local level, particularly around issues that affect services for individual infants, toddlers, and their families. They found that the funding of services for individual families and their children was the overriding concern among community personnel and families. Limited forms of coordination were evidenced in fund-raising activities, in the design and delivery of in-service training programs, and in the preparation of grant applications. Schafft, et al. found that coordination efforts at the local level rarely focus on methods to identify and overcome gaps in community or regional early intervention systems, or methods to coordinate child find and tracking systems.

One action the two Departments have taken to increase coordination at the State level is the interagency agreement which designates Resource Access Projects funded by ACYF as liaisons to State education agencies (SEA), and charges them with facilitating agreements between Head Start and SEAs and, at the local level, between local education agencies and Head Start programs. 46 such agreements existed by the end of 1987, addressing such mutual concerns as child find, training, and joint services.

One mechanism to address service gaps is the State Interagency Coordination Council (ICC) established by the Handicapped Infants and Toddlers Program. During the first year of the program, each State was directed to establish an ICC comprised of 15 members to advise the Governor and the designated State agency administering the Handicapped Infants and Toddlers Program. As of December 31, 1987, 13 States were using previously established Councils, 25 States had established new Councils, and 17 States and Insular Areas were in the process of appointing new Councils (NASDSE, 1988). The activities of the councils are intended to facilitate the planning and implementation of interagency coordination on the State level.

Too little is known about Federal funding levels to determine the adequacy, stability, or withdrawal of resources.

It is clear from the preceding descriptions of Federal programs that a wide range of funding and services are potentially available for early intervention. Appendix C presents the current appropriation for each of the 16 programs. However, the extent to which these programs contribute funds to early intervention is not known. Schafft, et al. (l987) found "that none of the various agencies within the 2 Departments maintained data on services and funding specifically allocated or spent on this population" (p. 24).

Given the varied purposes of the 16 programs, it is not known what proportion of the funds from these programs support early intervention services. With the exception of the Handicapped Infants and Toddlers Program, the programs do not have early intervention as their central focus. Consequently, the content and nature of their reporting and fiscal tracking requirements are not designed to describe or document the number of early intervention recipients, early intervention services provided, or funds expended. Thus, the two Departments cannot at this time estimate the amount of Federal funds being expended on early intervention services.

Unable to determine the amount of Federal funding for early intervention services directly from Federal agency records, Schafft, et al. (1987) attempted to determine the level of Federal funding that was available at the State and local levels. However, the effort was thwarted by the various approaches used to flow funds to State and local agencies. States often combine Federal and State resources; they may combine county funds with State and Federal resources; and they may relabel a program. The variation in the distribution of Federal funds and the use of such funds at State and county levels make it difficult to track the amount of Federal funding being expended on early intervention services. For example, the Developmental Disabilities Basic State Grant Program issues a request for proposals and the State admin-istering agency applies. The money received by the administering agency may then be sent to local governments, or to providers of client services, and may be enlarged by State and county funds even though there are no Federal matching requirements. The Parent and Child Centers which serve children from birth through ywo years of age are, however, funded from the national office as demonstrations.

Another example is provided by Head Start whose funding flows to Federal regional offices where local public agencies, private nonprofit organizations, and school systems submit applications for review every three years. Funds flow from the Federal agency directly to the service providers. The Parent and Child Centers which

serve children from birth through three years of age are, however, funded by the national office as demonstrations.

While it is currently impossible to estimate the level of Federal funding being spent on early intervention services for infants and toddlers with handicaps and their families, some information exists about Federal sources that are primarily used by States to finance such services. According to Gallagher, et al. (l988) representatives from each State agency responsible for administering the Handicapped Infants and Toddlers Program reported that their States used from 4 to 15 different sources of funds. States on the average used funds from 11 Federal programs to finance early intervention services. The most frequently used sources cited were private insurance, Medicaid, and State health funds.

The scarcity of information specific to this population makes it impossible to estimate the amount of Federal funding that actually supports early intervention services. Not only does this make it difficult to establish a baseline of services at the outset of the Handicapped Infants and Toddlers Program, but it also creates additional difficulties in administering the program. The statute requires that State and local expenditures for early intervention services not be supplanted or reduced by the new Federal funds, but be increased or supplemented. The potential for displacement of resources among these 16 programs may be difficult to monitor utilizing traditional reporting requirements or Federal audit procedures. Given the variety of funding approaches and diversity of discretion left to States in establishing priorities, new mechanisms will be required for determining whether programs are withdrawing or reducing funding support because of the Handicapped Infants and Toddlers Program.

Conclusion

The 16 programs identified in the Departments of Education and Health and Human Services provide evidence of a significant Federal commitment to the early intervention services defined in the Handicapped Infants and Toddlers Program. A significant level of Federal funding is potentially available to support these services. However, the actual funding level for early intervention now depends on competition within all but one program for resources to support a variety of service needs. Gaps in the provision of early intervention services are likely due to various factors, including difficulties in coordinating funding sources, and in coordinating the design and implementation of policy and services. These 16 Federal programs may contribute

to the provision of early intervention services, but they have not yet resulted in comprehensive statewide systems of early intervention.

Increased interagency coordination should contribute to achieving a better fit between the provision of early intervention services and early intervention needs. However, the 16 Federal programs were never legislatively intended to sum to a whole. Rather, they were designed to be programmatically, socially, and politically responsive to a broad variety of special populations and human service needs. Therefore, although Federal resources offer an array of opportunities for assisting States to provide early intervention services, legislative purposes of the programs militate against a consistent and cumulative effort, and create a difficult and complex coordination task for responsible State agencies.

One of the most immediate challenges to State-level coordination is to make known the potential resources for early intervention. Two recent studies (Schafft, et al., 1987 and Gallagher, et al., 1988) have evidence indicating that no single person or agency in a State was aware of all the potential resources for early intervention. Interagency coordination to share and review such information would strengthen the design of comprehensive early intervention systems.

C H A P T E R 3

COORDINATION OF FEDERAL PROGRAMS FOR INFANTS AND TODDLERS WITH HANDICAPS

Coordination of activities on the Federal level is essential to the successful provision of early intervention services in the States. The activities designed to facilitate coordination address three goals established in the legislation. These goals are to assist a State:

- to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families;

- to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources, including public and private insurance coverage; and

- to enhance its capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to handicapped infants and toddlers and their families. (Education of the Handicapped Act, Part H-Section 671(b)).

The Departments of Education and Health and Human Services are acting jointly to develop and implement policies, procedures and practices that will assist States in meeting the requirements for comprehensive statewide systems consistent with the Handicapped Infants and Toddlers Program. A major step toward coordinating their efforts was taken in October 1987, with the signing of a Memorandum of Understanding by agencies within the two Departments (see Appendix D). Participating agencies included: the Office of Special Education and Rehabilitative Services (OSERS), the Office of Maternal and Child Health (MCH), the Administration for Children, Youth and Families (ACYF), and the Administration on Developmental Disabilities (ADD). The memorandum established a Federal Interagency Coordinating Council on Early Intervention Services (FICC) to mobilize and access national resources for the implementation of the Handicapped Infants and Toddlers Program and to coordinate agency efforts in the two Departments. Additional agencies involved in the provision of early intervention services will be added to the

Council in 1988, e.g. the National Institute of Mental Health and the Health Care Financing Administration.

The remainder of this chapter describes the coordination, collaboration, and communication activities that the two Departments have initiated or intend to initiate.

Comprehensive Statewide System

The joint activities of the two Departments have been designed to assist States to develop and implement comprehensive statewide systems, according to the timelines delineated in Section 676 of the EHA Amendments of 1986. Fourteen components are contained within a comprehensive statewide early intervention system:

- a definition of "developmental delay" to be used by the State in carrying out this Act;
- a timetable that ensures that appropriate early intervention services will be available to all handicapped infants and toddlers prior to the fifth year of a State's participation under Part-H;
- a timely, comprehensive, multidisciplinary evaluation of each identified child, including the needs of the family to assist in the child's development;
- an individualized family service plan for each child;
- a comprehensive child find system;
- a public awareness program;
- a central directory of early intervention services and resources;
- a comprehensive system of personnel development;
- policies and procedures to ensure that personnel are appropriately and adequately trained;
- a single line of responsibility in a lead agency designated by the Governor;

- a policy pertaining to the contracting or making of other arrangements with service providers to provide early intervention services;

- a procedure for securing timely reimbursement of funds;

- procedural safeguards for clients of the system; and

- a system for compiling data on services and service populations.

Several efforts are underway to assist States in developing and implementing these components. One major effort is represented by a technical assistance contract, funded by the Office of Special Education Programs (OSEP), Department of Education, in conjunction with the Office of Maternal and Child Health, Department of Health and Human Services. This contract, known as the National Early Childhood Technical Assistance System (NEC*TAS), assesses the needs of the States and other jurisdictions that participate in the Handicapped Infants and Toddlers Program and delivers technical assistance in response to those needs.

Technical Assistance to States

NEC*TAS represents a consortium of six agencies comprised of multidisciplinary professional and parental expertise. The composition of the consortium, in many ways, reflects the Federal interagency coordinating efforts. The system is administered by the Frank Porter Graham Center, University of North Carolina at Chapel Hill. Two of the collaborative agencies, the Georgetown University Affiliated Program and the National Center for Clinical Infant Programs, have a long history as technical assistance providers with funding from MCH. In addition, the Georgetown University Affiliated Program receives funds from ADD. The administering agency and two collaborative agencies, the National Association of State Directors of Special Education (NASDSE) and the National Network of Parent Centers, have a history as technical assistance providers with funding from OSERS. The sixth collaborative agency is the Department of Special Education at the University of Hawaii, which primarily provides technical assistance in the Pacific Basin.

NEC*TAS has six major responsibilities related to the provision of technical assistance. These are:

- provision of technical assistance to the States, based on needs identified annually;
- coordination of technical assistance with other technical assistance providers, such as the Resource Access Projects funded by the ACYF, to aid Head Start projects and the Regional Resource Centers funded by OSEP to provide technical assistance to State Education Agencies;
- logistical support for a major annual early intervention conference;
- logistical support for 2 to 4 topical meetings annually;
- development of a clearinghouse for indexing and coordinating state-of-the-art information on early intervention and to be used by technical assistance providers and;
- development of a national directory containing names, addresses, and phone numbers of State agency officials involved with the Handicapped Infants and Toddlers Program, as well as a description of discretionary programs, indexed by State.

Jointly Sponsored National Meetings

In 1987, OSEP and MCH conducted a national meeting for representatives from the State agencies designated to administer the Handicapped Infants and Toddlers Program and from State educational agencies. In addition, parent representatives and professionals representing multiple disciplines participated. The meeting provided an opportunity for the two agencies to clarify Federal requirements for administering the Handicapped Infants and Toddlers Program. It also provided the Federal programs distributing early intervention funds an opportunity to have their recipients identify and define potential impediments to implementing comprehensive early intervention systems.

FICC, with logistical assistance from NEC*TAS, plans to conduct a similar meeting in July 1988. The meeting is designed to anticipate policy and implementation issues, to review the first year of the

Handicapped Infants and Toddlers Program implementation and to establish direction and priorities for continuing the initial momentum. A topical meeting is planned in 1988 to develop the philosophy, policy, and procedures for the development and use of Individualized Family Service Plans. National experts in the area of family services, representatives of the two Departments, parent representatives, and staff from NEC*TAS will be involved. A topical meeting is also planned on the issue of coordinating payments for early services. FICC plans to cosponsor national meetings that formerly were planned and managed by single agencies, for example, include the 1988 Partners for Progress II and the Surgeon General's Conference: "Building Community-Based Service Systems for Children with Special Health Care Needs."

Topical Meetings to Develop Philosophy, Policy and Procedures for Major Program Components

In 1988, NEC*TAS will conduct regional meetings to assess individual State needs. Initial needs identified by States will be addressed through individualized technical assistance agreements between each State and NEC*TAS. The agreements will provide for a variety of resources to the States to meet their needs, such as topical meetings (e.g., finance issues) conducted by NEC*TAS as well as on-site consultations in the States.

The development of interagency agreements between Federal agencies to coordinate efforts on specific issues relating to the implementation of a comprehensive statewide system is another major effort of FICC. An interagency agreement now exists between MCH and ACYF, effective through 1989 to provide for the delivery of technical assistance on nutrition, dental hygiene, and health issues through Public Health Services technical assistance providers. FICC will explore additional interagency agreements related to training, technical assistance, and services.

Facilitating Coordination of Payments

A major challenge to the successful implementation of statewide comprehensive systems of early intervention is the ability of State agencies and local service providers to identify and coordinate resources for payment of those services. To assist States in meeting this challenge, a five-year research institute has been funded. Located at the University of North Carolina, the Policy Institute was

funded by OSEP and is examining the policy issues related to the financing of early intervention services. This institute is conducting national surveys of current practices as part of an integrated research program on policy and finance in early intervention (c.f., Gallagher, et al., 1988). In addition, the Administration on Developmental Disabilities funded the preparation of a monograph in which Utah State University will describe the financial resources available for early intervention services, the costs of alternative forms of early intervention, and the way in which intervention services can be paid for under the Handicapped Infants and Toddlers Program.

The development of information about those receiving and needing early intervention services and of reporting systems on the State level is also crucial to ensuring the coordination of payment for services. Schafft, et al. (1987) reported significant limitations in current State information and reporting systems. Congress has provided States with a four-year phase-in period for meeting reporting requirements (i.e., the system for compiling data must be in effect by the beginning of the fourth year of a State's participation). In the summer of 1987, the Department of Education defined the minimum parameters for meeting the requirements for an information and reporting system for the Handicapped Infants and Toddlers Program. The information requirements include: the number of infants and toddlers with developmental delays receiving early intervention services; the number of infants and toddlers with developmental delays in need of early intervention services; the number of infants and toddlers receiving what types of early intervention services; the numbers and types of early intervention personnel employed and needed; and the amount of Federal, State and local expenditures for early intervention services. For year four of a State's participation in the Handicapped Infants and Toddlers Program, these requirements will form part of the grant application.

Obtain Information About Those Who Receive and Need Early Intervention

Within States, interagency coordination issues are an essential part of developing and implementing these reporting requirements. In order to meet reporting requirements, States must decide who is eligible for services; that is, they must define the infant and toddler population that will be served and develop eligibility requirements. Issues of definition and eligibility criteria must be reconciled across agencies

Coordinate Agency Reporting Requirements

before any such information can be aggregated. Further, systems and procedures for obtaining information across agencies need to be designed, developed, and implemented. Towards this end, the Department of Education is proposing to establish a priority to assist States in developing such information systems under the Handicapped Children's Early Education Program, Education of the Handicapped Act.

Further, the two Departments are coordinating their technical assistance activities to assist States in this undertaking. For instance, NEC*TAS is focusing on definitional issues through the dissemination of examples, preparation of issue papers, and direct consultation. A complementary effort is being planned by the North Carolina Policy Institute to identify model data systems being developed or implemented by the States. Additional technical assistance to representatives of the State agency responsible for administering the Handicapped Infants and Toddlers Program is being planned through an OSEP data support contract for design and development of information systems.

Coordinate Technical Assistance Activities

Consistent with the findings reported earlier by Gallagher, et al. (1988), it is evident that a need exists to assist States in identifying potential Federal sources of early intervention funds. Further, this study documented the modest coordination of Federal funds occurring at the State level. The two Departments, through FICC, intend to address these issues. FICC will invite the Health Care Financing Administration (HCFA) to join FICC, so that health care financing resources can be better coordinated on the Federal level. Descriptions of those Federal programs that can provide early intervention resources for programs and services will be disseminated to State Interagency Coordinating Councils and representatives from the State agency responsible for administering the Handicapped Infants and Toddlers Program. Finally, NEC*TAS will support several topical meetings in 1988 and 1989 to discuss impediments to and potential solutions for facilitating the coordination of payment for early intervention services.

Assist States To Identify Potential Sources of Early Intervention Funds

In addition to efforts to coordinate the flow and use of funds from ongoing sources of Federal funding for early intervention, attention is also being focused on discretionary programs. FICC has estab-

lished a subcommittee to evaluate the possibilities for coordinating and collaborating the agencies' various discretionary activities.

Expanding and Improving Early Intervention Services

The two Departments have many efforts under way to improve and expand early intervention services. FICC is an important mechanism for coordinating these efforts. The Memorandum of Understanding that established FICC states the Council's mission as follows:

> To develop specific action steps which promote a coordinated, interagency approach to sharing information and resources in the following areas:
>
> - Regulation, program guidance and priorities;
> - Parent participation;
> - Identification of children;
> - Materials and resources; and
> - Training and technical assistance,

FICC intends to issue guidance on these areas to programs and agencies funded by the members' respective Federal agencies. A sample of actions taken or planned in each area that will result in the expansion or improvement of early intervention services is presented briefly in the following sections.

Regulation, Program Guidance, and Priorities

- Information and policy exchanges are planned between the two Departments regarding regulations that affect infants and toddlers with handicaps and their families. For instance, discussions between the two Departments will be held in 1989 regarding the final regulations for the Handicapped Infants and Toddlers Program. Both agencies will share preliminary reviews of draft proposed regulations.

° Information will be shared regarding selected priorities proposed by the two Departments. A subcommittee of FICC is to be established to identify priorities that would benefit from joint funding by the two Departments. One potential area for joint funding is the discretionary activities dealing with the identification and transfer of effective early intervention strategies into day care environments for infants and toddlers with handicaps. Statewide information management systems and data systems are also areas in which joint priorities may occur.

° Discretionary program goals will be discussed to ensure the development of service delivery models that are family centered and community based. The goals of these discussions are to develop models that enable the child to live at home with the family while receiving services, to ensure that services are delivered in the least restrictive environment and to ensure that the provision of services is coordinated among and within agencies.

Parent Participation

° FICC is committed to family involvement in all aspects of the implementation of the Handicapped Infants and Toddlers Program, including policy development, program planning, service delivery, and evaluation. The range of family involvement will be ensured in several ways, including the appointment of family members to the FICC, the invitation of a parent representative from each State Interagency Coordinating Council to the National Early Intervention Conference in 1988, the funding of discretionary programs to develop and evaluate models of parent and family involvement, and the appointment of parents to advisory councils for projects funded by the discretionary programs and for technical assistance programs.

° Technical assistance providers will be encouraged to prepare materials on parenting that are geared to strengthening families and that will help families gain access to needed services.

Identification of Children

° The two Departments plan to develop models for coordinating child screening activities (e.g., Early Periodic Screening, Diagnosis and Treatment (EPSDT), MCH Newborn Screening for Metabolic

Disorders, Child Health Assessments, Child Find). In addition, substantial efforts will be made to coordinate data tracking systems and public awareness for child find activities between the two Departments.

Materials and Resources

° FICC will encourage the identification of private resources as well as public resources and the development of both public and private partnerships in serving and financing services for infants and toddlers with handicaps and their families.

° Agencies in the two Departments plan to develop information on resources and programs in areas identified as nationally significant, such as infant health and development, multi-cultural concerns and interagency coordination. These will be disseminated to the State Interagency Coordinating Councils, parents, and other interested public and private providers. An example of one such effort is a manual by the Early Intervention Consortium and funded by ADD describing the administrative practices that facilitate the implementation of early intervention services. The manual was disseminated in 1988. The major commitment to early intervention by national voluntary organizations and agencies will be recognized and utilized.

Training and Technical Assistance

° The two Departments have collaborated on a number of training issues and are developing plans for future collaboration. For example, OSEP funded an Institute on Personnel Preparation at the University of North Carolina to study and develop effective procedures and materials for training professionals from diverse disciplines to work with infants and toddlers with handicaps and their families. MCH supplemented this award to include the training of physicians. The two Departments plan to coordinate sessions on the topic of pre-service and in-service personnel preparation at the 1988 National Early Intervention Conference. These sessions will describe the training opportunities available through ADD, OSEP, and MCH and the extent to which these training opportunities complement or supplement one another.

° Coordinated technical assistance activities have been a major area of effort between the two Departments. For example, the Departments jointly sponsored an annual conference on early intervention in 1987, and another is planned for 1988, through FICC. MCH and ADD have included workshops to inform pediatricians in leadership positions about the Handicapped Infants and Toddlers Program.

° Technical assistance providers funded by various agencies in the two Departments have been working together to ensure that their efforts are not duplicative and that efforts are coordinated whenever possible. Liaison activities, for example, occur between NEC*TAS and the Regional Resource Centers, funded by OSEP, the Resource Access Projects (RAP), funded by ACYF, the American Association of University Affiliated Programs, funded by ADD, and the national projects funded by MCH (e.g., Association for the Care of Children's Health, Federation for Children, and Georgetown University Networking Center).

Summary

Since the enactment of the Handicapped Infants and Toddlers Program, the Departments of Education and Health and Human Services have made significant efforts to jointly assist States to develop and implement comprehensive statewide early intervention programs and services, to facilitate the coordination of payments for early intervention services, and to enhance the national capacity to expand and improve such services. Both Departments are designing initiatives to create flexible interagency systems with the capacity to provide services in a full continuum of service delivery settings. Their goal is to develop policies, procedures, practices and structures that are coordinated and fully responsive to the needs of each child and family who requires early intervention services. The two Departments are committed individually and jointly to undertaking those policy and leadership actions necessary to achieve a match between the service delivery system and the needs of infants and toddlers with handicaps and their families.

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APPENDIX A

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APPENDIX B

DESCRIPTIONS OF PROGRAMS PROVIDING SUPPORT FOR EARLY INTERVENTION

Introduction

The 16 programs described in Appendix B are either programs that authorize early intervention services or are broad enough to provide these services. Many of them are targeted to the poor or to individuals with low incomes. They are administered by the Department of Education or the Department of Health and Human Services. Descriptions are based on the status of these programs as of December 31, 1987. A table of fiscal years 1987 and 1988 appropriations for these programs can be found in Appendix C.

Several examples of programs that can improve the quality of early intervention services are also provided in Appendix B. Such programs are funded by discretionary grants, often for limited periods of time. They include grants for: (1) the development of model programs (demonstrations), (2) the replication of model programs (outreach), (3) research, (4) personnel training, and (5) technical assistance. Within statutory limits, priorities are established by program offices. Although these programs are beyond the scope of the report, it is worth noting some of them because of their potential impact upon the quality of early intervention services.

HANDICAPPED INFANTS AND TODDLERS	
Legislative Authority:	Education of the Handicapped Act, Part H
Administering Agency:	Division of Educational Services Office of Special Education Programs Office of Special Education and Rehabilitative Services Department of Education
Type of Grant:	Formula Grant

The Education of the Handicapped Act Amendments of 1986 authorized a new program to provide assistance to States to: (1) develop and implement a statewide comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families; (2) facilitate the coordination of payment for early intervention services from Federal, State, local and private sources; and (3) enhance the capacity of States to provide quality early intervention services and expand and improve existing early intervention services being provided to handicapped infants and toddlers and their families. "Handicapped infants and toddlers" are defined as children from birth through age two who are experiencing developmental delays in cognitive development, physical development, language and speech development, and/or self-help skills, or those who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. At their discretion, States may include children at risk of having substantial developmental delay if early intervention services are not provided.

A statewide system must include the following components: a definition of "developmentally delayed"; timetables for providing services; a multidisciplinary evaluation of each handicapped infant or toddler and the needs of the family; an individualized family service plan for children served; a comprehensive child find system; a central directory of State services, resources and experts; a public awareness program; a comprehensive system of personnel development; a single line of responsibility in a Governor-designated lead agency; policies, including contracting policies, relating to arrangements with service providers; a procedure for timely reimbursement of funds; procedural safeguards; policies and procedures for the establishment and maintenance of personnel standards; and a data collection system. In addition, a State Interagency Coordinating Council, composed of parents, providers and professionals, must be appointed by the Governor. The statewide system must be in effect by the beginning of the

fourth year. States must provide information and assurances that the system is in effect to receive funding for the fifth and succeeding years. Funds are allocated on the basis of the proportion of children from birth through age two in the general population.

During fiscal year 1987 (the first year of the program), all eligible agencies participated. Applications indicated that 46 States expected to allocate at least a portion of their grants to improve or expand direct services. However, at present no data on the number of handicapped infants and toddlers served are available. Initial data should be available by the end of fiscal year 1988.

PROGRAMS FOR HANDICAPPED CHILDREN -- PROGRAMS OPERATED BY STATE AGENCIES (Chapter 1 Handicapped Program)	
Legislative Authority:	Education Consolidation and Improvement Act of 1981, Title 1, Chapter 1, Section 554(a)(2)(B)
Administering Agency:	Division of Assistance to States Office of Special Education Programs Office of Special Education and Rehabilitative Services Department of Education
Type of Grant:	Formula Grant

This program funds grants to States to provide special education and related services to handicapped children from birth through age 20 in State-operated or supported facilities and programs. Funds are distributed on the basis of the number of children, aged birth through 20, States counted as served under the program on October 1 of the fiscal year for which funds are appropriated.

Data by age category on the number of children served was first collected at the beginning of fiscal year 1988. States reported that they were serving 30,487 handicapped children, aged birth through two. This comprises approximately 12 percent of all children counted as served on October 1, 1987. Reauthorization of the program is currently pending in the Congress.

SERVICES FOR DEAF-BLIND CHILDREN AND YOUTH	
Legislative Authority:	Education of the Handicapped Act, Part C, Section 622
Administering Agency:	Division of Educational Services Office of Special Education Programs Office of Special Education and Rehabilitative Services Department of Education
Type of Grant:	Discretionary Grant

The program for deaf-blind children authorizes funding to public or nonprofit agencies, institutions, or organizations to assist State educational agencies in providing special education and related services (as well as vocational and transitional services) to deaf-blind children from birth through age 21. Authorized services include the diagnosis and educational evaluation of children at risk of being certified as deaf-blind; and consultative, counselling and training services for the families of deaf-blind children.

The regulations implementing the law give first priority to direct services for deaf-blind children "...to whom States are not obligated to make available a free appropriate public education under Part B of the Education of the Handicapped Act and to whom the State is not providing those services under some other authority [e.g., the Chapter 1 Handicapped Program] ..." (34 C.F.R. sec. 307.11). Second priority is given to providing technical assistance to States to ensure that they are able to provide services to the deaf-blind children they are required to serve. Funds remaining after these two priorities have been met may be used to provide services to school-aged children whom States are already required to serve.

States are required to report annually the number of deaf-blind children served by age, severity and nature of deaf-blindness, and the types of services provided. They are not required to identify how many children within an age group received direct services and how many were counted as served because States received technical assistance.

As of August 1987, a total of 259 deaf-blind children, aged birth through two, were counted as served. Of this number, 12 were less than a year old, 98 were one year old, and 149 were two years old.

ASSISTANCE FOR EDUCATION OF ALL HANDICAPPED CHILDREN	
Legislative Authority:	Education of the Handicapped Act, PartB
Administering Agency:	Division of Assistance to States Office of Special Education Programs Office of Special Education and Rehabilitative Services Department of Education
Type of Grant:	Formula Grant

Part B of the Education of the Handicapped Act mandates the provision of a free appropriate public education to all handicapped children aged 3 through 21 and provides a timetable for serving these children. The mandate does not apply to children aged 3 through 5 or 18 through 21 where serving these children would be inconsistent with State law or practice or the order of any court. However, the Education of the Handicapped Amendments of 1986 require that States must serve all handicapped children aged 3 through 5 years by 1990 or 1991, depending upon appropriation level, in order to receive funds for these children under this program as well as under the Preschool Grants Program after the mandate is effective.

Funds are allocated on the basis of a count of children, aged 3 through 21, served by States on December 1 of the fiscal year for which funds are appropriated. The program does not mandate services to handicapped infants and toddlers or provide funding for those infants and toddlers served. However, these funds can be used to serve them.

While the Committee does not include children from birth up to three within the priority or within the timetable for services, it points out that funds under the [Education for the Handicapped] Act, as in existing law, may be spent for providing services to these children. The Committee wishes to encourage the provision of such services to such children, and points out that early identification, screening and assessment, and parent counselling are specifically included with the definition of "related services" which should be appropriately provided to handicapped children for this purpose. (Senate Report No. 94-168, June 2, 1975.)

By law, 75 percent of the funds allocated to a State must be distributed to local educational agencies (LEAs) and intermediate education agencies (IEUs). Twenty-five percent may be retained by the State. Of this amount, up to 5 percent may be used for administrative costs and up to 20 percent may be used for direct and support services or for the administrative costs of monitoring and complaint investigation to the extent that such costs exceed those incurred in fiscal year 1985.

Since LEAs and IEUs are apt to use the funding they receive for children enrolled in their educational programs, it is likely that most, if not all, of the funds used for infants and toddlers derives from the 20 percent that States can use to provide support and direct services to handicapped children.

There are no data available that indicate how many handicapped infants and toddlers received services under the program or what services they received.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

HEAD START	
Legislative Authority:	Head Start Act (42 U.S.C. 9831 et seq.)
Administering Agency:	Head Start Bureau, Administration for Children, Youth, and Families Office of Human Development Services Department of Health and Human Services
Type of Grant:	Formula allocations among States Discretionary grants to local Head Start agencies

The four primary components of the Head Start Program are education, social services, parent involvement, and health services. Health services include nutrition, health, and mental health services.

The program serves children ages birth through five, most of whom are between three and five years old. Ninety percent of the children served under Head Start must be from low-income families as specified in the Head Start Act. Funds are allocated to States based on the number of children, birth through age five, in poverty and the number of children through age 18 in families receiving Aid to Families with Dependent Children.

In the Omnibus Budget and Reconciliation Act of 1981, Congress mandated that beginning in 1982 at least 10 percent of the enrollment opportunities in Head Start must be available for children with handicaps and that services must be provided to meet their special needs. In fiscal year 1987, 12.7 percent, or 65,275, of all children from birth through age five were certified as handicapped by professionals from outside Head Start.

Two Head Start programs--the Migrant Head Start Program and the discretionary Parent and Child Centers Program--serve infants and toddlers. The goal of these programs is to improve the overall development of the infants and toddlers served. The programs emphasize the prevention of developmental deficits, increasing parental knowledge of their children and their knowledge of parenting, and strengthening the family unit. The programs include developmental activities, comprehensive health care for infants and toddlers, nutritional education, and social services for the family.

The Migrant Head Start and Parent and Child Centers Programs served 13,368 children aged birth through two in fiscal year 1987. Of this number, 3,233 were under one year of age; 3,728 were one year old; and 6,407 were two years old. A total of $28,335,000 was spent on these children. Six percent of the infants and toddlers served are estimated to have had handicapping conditions and eighty percent are estimated to have been at risk of developmental delay, either through inadequate health care, parent stress, or poor nutrition.

MEDICAID	
Legislative Authority:	Social Security Act, Title XIX
Administering Agency:	Health Care Financing Administration Department of Health and Human Services
Type of Grant:	Federally-Matched Entitlement

The program provides health coverage for low-income persons. Persons eligible for Medicaid are:

- **The categorically needy** - Those persons receiving cash assistance under Aid to Families with Dependent Children, Supplemental Security Income, or children under the foster care or adoption assistance program. Included are children and pregnant women who have qualified categorically needy status and those who are covered under optional provisions.

Services for the categorically needy include inpatient and outpatient medical services, physicians and dentists' services, and early and periodic screening, diagnosis and treatment (EPSDT) for children 21 years of age and under. EPSDT provides comprehensive and preventive health services to ascertain physical and mental defects and to provide treatment to correct or ameliorate defects and chronic conditions found

through the diagnostic services. The services provided through EPSDT include initial and periodic screening for growth and development assessment and treatment, including such discretionary services as physical, occupational, and speech therapy.

- **The medically needy** - At a State's option, those low-income persons who meet the categorical but not the financial criteria for regular Medicaid eligibility. If the medically needy are covered, a State must provide medical assistance to eligible children under 18.

Under Federal law, only a limited number of services must be provided for the medically needy. According to a recent study, "...all States, though, have elected to provide medically-needy children a benefit package that is the same or nearly the same as the one available to the categorically needy." (Harriet Fox, with Ruth Yosphpe, "Medicaid Financing for Early Intervention Services," unpublished report, June 1987, p. 23)

- **Women and children from birth through age five** - This program was authorized by the Omnibus Budget Reconciliation Act (OBRA) of 1986. Under the program, States have the option to extend medical services to pregnant women and children from birth through age five for those persons whose family income does not exceed 100 percent of the non-farm federally defined poverty level. The provision extended coverage to children through age five in one-year increments, beginning with infants in fiscal year 1987. As of July 1987, 26 States had elected to exercise the option to extend coverage to these populations. The OBRA of 1987 revised the program by providing States with the option of extending coverage to pregnant women and infants up to age one whose family income does not exceed 185 percent of the Federal poverty level. The OBRA of 1987 also accelerated the coverage of children to age five and extended coverage to children up to age eight.

At their option, States may provide services such as clinic services, home health services, and case management services to assist people to gain access to needed medical, social, educational services, as well as speech, physical, or occupational therapy, and psychological/psychiatric services. The OBRA of 1986 permits States, under a waiver, to include all or part of the cost of home or community-based services (except room and board) for persons who would otherwise be placed in a hospital, skilled nursing facility, or intermediate care facility, if the cost of such care is not greater than it would be in these facilities.

In fiscal year 1986, Medicaid spent $3,511,585,244 on children aged six and younger and served a total of 4,815,749 such children. There are no data on the number receiving early intervention services.

MATERNAL AND CHILD HEALTH BLOCK GRANT	
Legislative Authority:	Social Security Act, Title V
Administering Agency:	Office of Maternal and Child Health Bureau of Maternal and Child Health and Resources Development Health Resources and Services Administration Public Health Service Department of Health and Human Services
Type of Grant:	Block Grant

The block grant was created by the Omnibus Budget and Reconciliation Act of 1981, which combined the categorical programs authorized by Title V and selected other programs. The grants are for promoting, planning, coordinating, providing, and evaluating health services for mothers and children to age 21.

The goals of the program are: (1) to assure that mothers and children, especially those with low income or limited availability of health services, have access to quality health services; (2) to emphasize preventive measures, such as those to reduce infant mortality and prevent handicapping conditions, and to promote the health of mothers and children through primary pediatric and prenatal care; (3) to provide rehabilitative services to blind and disabled children eligible for Social Security Income under Social Security; and (4) to provide comprehensive services to handicapped children. Among the services provided are: prenatal and postpartum care; health care services (assessment, diagnosis, and treatment); prevention of substance abuse, accidents/injuries, child abuse and neglect, violence, stress, obesity, and lead poisoning; and comprehensive rehabilitation services for children with special health needs, including outreach, case management, family support, and coordination with other public and private agencies.

Funds are allocated as a formula grant to the States based partially on the proportion of low-income children, aged birth to 21, in the State in relation to the total number of children in the State. States must provide a "fair method" for distribution of block grant funds among competing programmatic priorities across needy populations. States must match every four Federal dollars with three State dollars.

CHILD WELFARE SERVICES	
Legislative Authority:	Social Security Act, Title IV-B
Administering Agency:	Administration for Children, Youth and Families Office of Human Development Services Department of Health and Human Services
Type of Grant:	Formula Grant

The program provides Federal assistance for public social services which are directed toward: (1) protecting and promoting the welfare of all children; (2) preventing or remedying, or assisting in the solution of problems that could result in the neglect, abuse, exploitation or delinquency of children; (3) preventing the unnecessary separation of children from their families by identifying family problems, assisting families in resolving these problems, and preventing breakup of the family where the prevention of child removal is desirable and possible; (4) restoring to their families children who have been removed, by the provision of services to the child and the families; (5) placing children in suitable adoptive homes, where restoration to the biological family is not possible or appropriate; and (6) assuring adequate care of children away from their homes, in cases where the child cannot be placed for adoption.

Services must be available on the basis of need for services. They cannot be denied on the basis of financial need or length of residence in a State. Services that can be provided as part of a plan for preventing children's removal from home include: homemaker services, day care, individual and family counseling, and arrangements for the provision of temporary child care to provide respite to the family for a brief period. The "Child Welfare Services State Plan Analysis FY 1983", the most recent analysis available, indicated that States had initiated a variety of activities intended to prevent the unnecessary separation of children from their families. These activities included implementing a parent aid program with emphasis on home visitors; developing a professional home care worker model; and utilizing volunteers to provide services to vulnerable children, such as the mentally retarded.

There are no data available regarding the number receiving early intervention services.

DEVELOPMENTAL DISABILITIES--BASIC STATE GRANT	
Legislative Authority:	Developmental Disabilities Assistance and Bill of Rights Act
Administering Agency:	Administration on Developmental Disabilities Office of Human Development Services Department of Health and Human Services
Type of Grant:	Formula Grant

The program provides grants to States to fund services for persons with developmental disabilities. Eligible persons are those with a severe and chronic disability which is manifested before the person reaches 22 years of age, which is likely to continue indefinitely, which results in functional limitations in 3 or more areas of major life activity (e.g., self-care, language, learning, mobility, self-direction, capability for independent living and economic self-sufficiency), and which requires lifelong or extended care, treatment, or services.

To receive funds, States must establish a State Planning Council to serve as an advocate for persons with developmental disabilities. A State plan is required, which must review the extent and scope of services being provided or to be provided to persons with developmental disabilities under other State plans for federally assisted programs, including those under the Education of the Handicapped Act and Maternal and Child Health.

For fiscal year 1986, States were required to select two of the four Federal priority areas: (1) alternative community living arrangements (which includes in-house services such as personal aides and attendants, family support services, foster care services, and respite care); (2) employment-related activities; (3) child development activities (which includes services to assist in the prevention, identification, and alleviation of developmental disabilities in children, including early intervention services, counseling and training for parents, early identification of developmental disabilities, and diagnosis and evaluation of such developmental disabilities); and (4) case management services (which includes those services to assist persons with developmental disabilities to gain access to social, medical, educational, and other services).

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, enacted on October 29, 1987, retained the four Federal priority areas but made clarifications in the definitions of each area. Handicapped infants and toddlers would be eligible for services under all of the Federal priority areas except "employment-related activities." However, because "child development services" are targeted to developmentally disabled children, most handicapped infants and toddlers would receive early intervention services under that priority area.

For fiscal year 1986, 22 States and territories reported providing services to children under the "child development" priority. In total, States served 10,984 children under the priority. No age breakdown of children served is available. Beginning with fiscal year 1987, States are required to have "employment-related activities" as one of their priority areas. States may elect one or more of the remaining Federal priority areas. No information is available at this time regarding the number of States that selected "child development" as a priority area in fiscal year 1987 or the number of children served in fiscal year 1987.

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH BLOCK GRANT	
Legislative Authority:	Public Health Service Act, Title XIX, Sections 1911-1920
Administering Agency:	Alcohol, Drug Abuse and Mental Health Administration Public Health Service Department of Health and Human Services
Type of Grant:	Block Grant

The Alcohol, Drug Abuse and Mental Health Block Grant, established by the Omnibus Budget Reconciliation Act of 1981, replaced funding for categorical programs which served the same goals. The program provides funds to States for projects to support prevention, treatment, and rehabilitation activities in the areas of alcohol and drug abuse, and grants to mental health centers for mental health services. Funds are distributed to States so that, nationally, spending for mental health is about equal to that for substance abuse services. States are required to spend about the same amount for mental health and substance abuse services as they did under the categorical programs. Approximately 50 percent of the funds is spent on mental health and 50 percent on substance abuse.

Although some handicapped infants and toddlers and their families may receive substance abuse services, it is likely that most of the funds spent on early intervention services are spent on mental health services. Therefore, the rest of this discussion is focused on these services.

States may use funds for the following mental health services: (1) services for chronically mentally ill individuals, including identification of chronically mentally ill individuals and assistance to such individuals in gaining access to essential services through the assignment of case managers; (2) identification and assessment of severely mentally disturbed children and adolescents and provision of appropriate services to such individuals; (3) identification and assessment of mentally ill elderly individuals and provision of appropriate services to

such individuals; (4) services for identifiable populations which are currently underserved in the State; and (5) coordination of mental health and health care services provided within health care centers.

The October 1986 Report to Congress on the Alcohol and Drug Abuse and Mental Health Services Block Grant (printed June 1987) provided summaries of State activities supported with fiscal year 1985 funds, the most recent year for which information is available. The report indicates that all States provided some mental health services for children and adolescents. In general, the report does not provide information about how extensive these services were or the ages or age groupings of children served. However, it is clear from the report that some funds, at least in some States, were expended for infants and toddlers with handicaps. For example, one State reported concentrating its mental health services on children nine years of age and younger; another reported funding an early intervention program to provide diagnosis and treatment for up to 220 children from birth to four years of age; and a third reported that it served disturbed children from birth.

Reauthorization of the program is currently pending in Congress.

COMMUNITY HEALTH CENTERS	
Legislative Authority:	Public Health Service Act, Section 330
Administrative Agency:	Bureau of Health Care Delivery and Assistance Health Resources and Services Administration Public Health Service Department of Health and Human Services
Type of Grant:	Discretionary Grant

This program funds community health care centers providing primary health services to medically underserved populations. By law, the centers must provide: primary health services; supplemental health services necessary for the adequate support of primary health services as appropriate; referral to providers of supplemental health services and payment for the provision of such services, as appropriate and feasible; environmental health services, as appropriate; and information on the availability and proper use of health services.

Primary health services authorized under law include the services of physicians and, where feasible, those of physician assistants and nurse clinicians; diagnostic laboratory and radiologic services, preventive health services (includ-

ing children's eye and ear examinations to determine the need for vision and hearing correction and well-child services); emergency medical services; transportation services required for adequate care; preventive dental services; and, as appropriate, pharmaceutical services.

The cost of services is adjusted to the patient's ability to pay. Funds to support the costs of operating the centers are provided by Federal grants, Medicaid, Medicare, third-party providers (e.g., insurance), patient fees, State, local, and other sources.

"Community Health Centers, A Quality System for the Changing Health Care Market," (National Clearinghouse for Primary Care Information, Fall 1986) reports that in fiscal year 1985, the most recent year for which data are available, approximately 5.1 million people used the centers. Of those served, approximately half lived in urban areas and half in rural areas; approximately 64 percent were members of minority groups; about 60 percent were under the poverty level and another 25 percent were between 100 and 200 percent of poverty; and 45 percent were children under 20.

There is no data on the number receiving early intervention services.

INDIAN HEALTH SERVICE	
Legislative Authority:	Snyder Act of 1921 and Indian Health Care Improvement Act
Administering Agency:	Indian Health Service Health Resources and Services Administration Public Health Service Department of Health and Human Services
Type of Grant:	Discretionary Grant

The program includes a direct health care delivery system, a tribal health care delivery system which is administered by tribes and tribal groups through contracts with the Indian Health Service, and the purchase of contract care from non-tribal providers. Health services provided include: patient care, prenatal and postnatal care, well-baby care, family planning, dental care, immunizations, and health education services. Funds are allocated based on the amount of funds area programs spent in the previous fiscal year, current program expenditures, and area funding priorities.

The Indian Health Service direct delivery system includes 45 hospitals, 65 health centers, 6 school health centers, and 267 smaller health stations and satellite clinics. The tribal health care delivery system consists of 6 hospitals, 70 health centers, 1 school health center, and 262 smaller health stations and satellite clinics. Various referral services are provided to Indians in urban settings through 33 urban health projects.

The Indian Health Service estimates that there are 8,400 children from birth through age three who have handicapping conditions in the areas served. Plans for the future include the establishment of local teams to evaluate and track children and to develop interagency agreements to provide services to them.

MIGRANT HEALTH	
Legislative Authority:	Public Health Service Act, Section 329
Administering Agency:	Bureau of Health Care Delivery and Assistance Health Resources and Services Administration Public Health Service Department of Health and Human Services
Type of Grant:	Discretionary Grant

Migrant health centers provide comprehensive primary health care to migrant and seasonal farm workers and their families. Programs are linked or integrated with hospital services and other health and social services existing within the area being served. Projects may provide services through a full year-round primary health care program; through a seasonal or temporary program, with services provided by a physician and/or nurse and specialty referral; or through a seasonal program that provides services with local health providers on a contractual arrangement. Services provided include: the services of physicians and, where feasible, physicians' assistants and nurse clinicians; diagnostic laboratory and radiology services; preventive health services, including children's eye and ear examinations, perinatal services, well-child services and family planning services; and emergency medical services. According to "Primary Care--Migrant Health Program," a report prepared by the program office, the 122 migrant health centers operate approximately 378 clinics located in over 300 rural areas in 35 States and Puerto Rico.

The Migrant Health Program found that in fiscal year 1987, 500,000 migrant and seasonal workers were served in the migrant health centers. Of this number,

38 percent were children under age 14. There are no data available on the number receiving early intervention services.

PREVENTIVE HEALTH AND HEALTH SERVICES BLOCK GRANT	
Legislative Authority:	Public Health Service Act, Title XIX, Sections 1901-1909
Administering Agency:	Centers for Disease Control Public Health Service Department of Health and Human Services
Type of Grant:	Block Grant

Established by the Omnibus Budget Reconciliation Act of 1981, the block grant replaced eight categorical grant authorities. Funds from the grants may be used for the following purposes: (1) preventive health service programs for the control of rodents and community- and school-based fluoridation programs; (2) establishing and maintaining preventive health service programs for hypertension; (3) community-based programs to demonstrate and evaluate optimal methods for organizing and delivering comprehensive preventive health services to defined populations, comprehensive programs designed to deter smoking and the use of alcoholic beverages among children and adolescents, and other risk-reduction and health education programs; (4) comprehensive public health services; (5) demonstrating the establishment of home health agencies where the services of such agencies are not available (but may not be used for direct provision of health services by these agencies) for emergency medical services systems and the establishment, expansion, and improvement of such systems (but funds may not be used for the costs of the operation of the systems or the purchase of equipment for the systems except as provided for under law); (6) feasibility studies and planning; and (7) services to rape victims and for rape prevention. Except for the allotment for the rape program, funds are distributed on the proportion of total funding received under the formerly authorized categorical programs. The law permits States to transfer up to seven percent of the funds received under this program for use by the State under Title V of the Social Security Act (Maternal and Child Health).

"Public Health Agencies 1987, An Inventory of Programs and Block Grant Expenditures" (Public Health Foundation, September 1987), reported State expenditures of Federal funds received under this program for various activities in fiscal year 1985, the most recent year for which data are available. The report indicates that in 10 States funds from the program were expended to support the same types of services as those supported under the Maternal and Child Health Services block grant. For example, of these 10 States, six reported they had expended funds for "maternal and child health." One State reported it had

expended funds on birth defects. One State reported it had expended funds on a variety of activities such as child health and development, speech and hearing, children's health services, and infant follow-up.

There are no data available regarding how many handicapped infants and toddlers were served in these ten States or how many may have been served in other States. However, the above-cited report indicates that less than 0.05 percent of Federal block grant expenditures were spent on maternal and child health activities or services for children with handicaps.

Reauthorization of the program is currently pending in Congress.

HEALTH CARE FOR THE HOMELESS	
Legislative Authority:	Stewart B. McKinney Homeless Assistance Act
Administering Agencies:	Bureau of Health Care Delivery and Assistance Health Resources and Services Administration and Alcohol, Drug Abuse and Mental Health Administratio Public Health Service Department of Health and Human Services
Types of Grant:	Three Discretionary Grants and One Block Grant

The four programs comprising health services for the homeless are: health services, mental health block grants, mental health demonstration programs, and substance abuse programs. The health services program, the mental health demonstration program, and the substance abuse program are funded by discretionary grants. The programs provide funding for health care services, including mental health and substance abuse services, to the homeless. The focus of the mental health programs is upon the seriously emotionally disturbed. Services provided include assistance in obtaining health and mental health services, outreach, counseling, and case management. Except for the substance abuse program, which is statutorily limited to adults, all the programs can serve infants and toddlers.

Since funds for the health services program were first awarded in December 1987, there are no data available on the number served. It is estimated that a total of 400,000 people will be served and that approximately one-third of them will be women and children under age 21.

There are no data available on the number of handicapped homeless infants and toddlers served under the mental health block grant.

SOCIAL SERVICES BLOCK GRANT	
Legislative Authority:	Social Security Act, Title XX
Administering Agency:	Office of Policy, Planning and Legislation Office of Human Development Services Department of Health and Human Services
Type of Grant:	Block Grant

This program consolidated Federal assistance to States for social services into a single grant to increase State flexibility in the use of funds to meet State needs. The program primarily provides social services to low-income persons.

The goals of the program are: (1) achieving or maintaining economic self-support to prevent, reduce, or eliminate dependency; (2) achieving or maintaining self-sufficiency, including reduction or prevention of dependency; (3) preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests, or preserving, rehabilitating or reuniting families; (4) preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care; and (5) securing referral or admission for institutional care when other forms of care are not appropriate or providing services to individuals in institutions.

States determine what services will be provided, who will be eligible for services, and how funds will be distributed. States submit a pre-expenditure report as an application, which provides information about the types of activities to be supported. For fiscal year 1986 (the most recent year for which data are available), States reported providing the following services, all of which can include services to handicapped infants and toddlers: (1) protective and emergency services for children (54 States); (2) day care for children (52 States); (3) disabled services (41 states); (4) prevention/intervention services, including family-centered early intervention (35 States); and (5) health-related services (36 States).

By law, States may transfer up to 10 percent of their funds for use under other block grant programs for health services, health promotion and disease prevention, or low-income home energy assistance. In fiscal year 1986, one of the four States transferring funds to other programs made a transfer to the Maternal and Child Health Block Grant Program.

No data are available regarding the number receiving early intervention services.

EXAMPLES OF PROGRAMS AFFECTING THE QUALITY OF EARLY INTERVENTION SERVICES

DEPARTMENT OF EDUCATION

CLEARINGHOUSE - DISSEMINATION

Administering Agency: Division of Educational Services
Office of Special Education Programs
Office of Special Education and Rehabilitative Services
Department of Education

Section 633 of the Education of the Handicapped Act (EHA) requires that of the three authorized clearinghouses one be established to disseminate information and provide technical assistance to parents, professionals, and other interested parties. Information about programs relating to the education of the handicapped under the EHA and other Federal laws will be distributed on a national basis. The clearinghouse will provide technical assistance to encourage participation in such programs, including referral of individuals to appropriate national, State, and local agencies and organizations for further assistance.

To meet this statutory requirement, the Office of Special Education Programs funds the National Information Center for Children and Youth with Handicaps. The Center provides parents, professionals and interested parties information on health, education, and social services for handicapped children from birth.

HANDICAPPED CHILDREN'S EARLY EDUCATION PROGRAM

Administering Agency: Division of Educational Services
Office of Special Education Programs
Office of Special Education and Rehabilitative Services
Department of Education

The Handicapped Children's Early Education Program consists of four components: demonstration projects funded for three years, with the opportunity for renewal; outreach projects funded for one to three years, with the opportunity for renewal; the National Early Childhood Technical Assistance System (NEC*TAS) contract funded for four years; and experimental projects funded for three years.

These projects include activities for handicapped children from birth through age eight. A substantial number of the total, 72 of the 102 projects funded in 1985-86 were directed toward handicapped infants and toddlers.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH PROJECTS

Administering Agency: National Institute on Disability and Rehabilitation Research
Office of Special Education and Rehabilitative Services
Department of Education

The Institute plans and conducts research, demonstrations, and related activities which directly affect the provision of vocational and other rehabilitation services to handicapped individuals, including infants and toddlers. In fiscal year 1986, the most recent year for which data are available, funding for projects dealing with infants and toddlers comprised about four percent of the total appropriation.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

CHILD AND ADOLESCENT SERVICE SYSTEMS PROGRAM

Administering Agency: National Institute of Mental Health
Alcohol, Drug Abuse and Mental Health Administration
Department of Health and Human Services

The Child and Adolescent Service Systems Program (CASSP) attempts to change the way in which services to severely emotionally disturbed children and adolescents are delivered by States and communities. Through a multi-agency approach, CASSP encourages interagency coordination and planning of services, as well as the development of a stronger mental health component within the broader child serving system. In addition, CASSP encourages family involvement in the planning and implementation of services. During the past year, CASSP has increased its emphasis on the special needs of children aged birth to five who are emotionally disturbed or at serious risk of emotional disturbance.

CLINICAL RESEARCH ON CHILD HEALTH

Administering Agencies: Center for Research on Mothers and Children
and Intermural Research Programs
National Institute of Child Health and Human Development
Health Resources and Services Administration
Public Health Service
Department of Health and Human Services

Both the Center for Research on Mothers and Children (CRMC) and the Intermural Research Programs (IMRP) support research pertaining to child health. CRMC awards grants to scientists at universities and private research centers; IMRP conducts research within its own office. CRMC funds projects aimed at prevention in five areas: (1) genetics and terontology; (2) pregnancy and perinatology; (3) endocrinology, nutrition, and growth; (4) mental retardation and developmental disabilities; and (5) human learning and behavior. IMRP conducts basic research in various topic areas ranging from molecular biology to developmental neurobiology.

SPECIAL PROJECTS OF REGIONAL AND NATIONAL SIGNIFICANCE

Administering Agency: Division of Maternal and Child Health
Bureau of Maternal and Child Health and
Resources Development
Health Resources and Services Administration
Public Health Service
Department of Health and Human Services

Fifteen percent of the funds appropriated for the Maternal and Child Health Block Grants can be used to support Special Projects of Regional and National Significance (SPRANS). SPRANS projects are of six types: research; training; genetic diseases testing; counseling and information; hemophilia diagnostic and treatment centers; and special Maternal and Child Health Improvement Projects that focus on the chronically ill or disabled child, mortality and low birth rate issues and early intervention.

UNIVERSITY AFFILIATED PROGRAMS TRAINING

Administering Agency: Administration on Developmental Disabilities
Office of Human Development Services
Department of Health and Human Services

The Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987, enacted October 29, 1987, authorized discretionary grants to university affiliated programs to support projects to train personnel to address the needs of persons with developmental disabilities in areas of emerging national significance. Training personnel in the area of early intervention programs was one of the three areas identified in these amendments. Such grants are to be used to provide training to allied health personnel and other personnel who provide or will provide interdisciplinary intervention to infants, toddlers, and preschool age children with developmental disabilities. The training projects must include instruction on methods of working and collaborating with professionals and families of children with developmental disabilities.

APPENDIX C

APPROPRIATIONS

DEPARTMENT OF HEALTH & HUMAN SERVICES

PROGRAM	FISCAL YEAR 1987	FISCAL YEAR 1988
1. Head Start	$1,130,542,000	$1,206,324,000
2. Medicaid	27,612,360,000	30,656,932,000
3. Maternal and Child Health Block Grant	496,750,000	526,570,000
4. Child Welfare Services	222,500,000	239,350,000
5. Developmental Disabilities Basic State Grant	56,500,000	58,401,000
6. Alcohol, Drug Abuse and Mental Health Block Grant	508,860,000	487,317,000
7. Community Health Centers	419,550,000	382,960,000
8. Indian Health Services	948,000,000	1,012,000,000
9. Migrant Health	45,400,000	43,466,000
10. Preventive Health and Health Services Block Grant	89,525,000	85,736,000
11. Health Care for the Homeless (includes funds appropriated for block grants for mental health in FY 1987 and 1988 funds appropriatedfor mental health demonstrations in FY 1987)	87,500,000	25,850,000
12. Social Services Block Grant	2,700,000,000	2,700,000,000

DEPARTMENT OF EDUCATION

PROGRAM	FISCAL YEAR 1987	FISCAL YEAR 1988
1. Handicapped Infants and Toddlers	$50,000,000	$67,018,000.
2. Programs for Handicapped Children (Chapter 1 Handicapped)	150,170,000	151,269,000
3. Assistance for Education of All Handicapped Children	1,338,000,000	1,431,737,000
4. Services for Deaf-Blind Children and Youth	15,000,000	14,361,000

APPENDIX D

A MEMORANDUM OF UNDERSTANDING

AMONG

THE OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

THE OFFICE OF HUMAN DEVELOPMENT SERVICES
THE ADMINISTRATION FOR CHILDREN, YOUTH AND FAMILIES
THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

AND

THE DIVISION OF MATERNAL AND CHILD HEALTH

TO MOBILIZE AND ACCESS
NATIONAL RESOURCES
FOR
THE IMPLEMENTATION OF PUBLIC LAW 99-457

The Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), the Acting Assistant Secretary of the Office of Human Development Services (OHDS), the Commissioner of the Administration for Children, Youth and Families (ACYF), the Director of the Division of Maternal and Child Health (MCH) and the Commissioner of the Administration on Developmental Disabilities (DD) hereby join forces to foster interagency support for young children with handicaps and their families. P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, extends the provisions of Public Law 94-142 to children from age three and creates a new Federal discretionary early intervention program for handicapped and at-risk infants and toddlers.

As administrators of agencies with respective responsibilities to implement the legislation, to assure the availability of preschool services in the least restrictive environment and to assist states in providing quality health services for handicapped infants and children, we support the intent of P.L. 99-457.

The legislation stresses the importance of a coordinated, multi-agency approach to implementation. In keeping with the intent of the law, this memorandum of understanding initiates plans for a national model for interagency linkages under our administrative leadership.

We hereby agree to establish and support a Federal Interagency Coordinating Council composed of representatives of the Office of Special Education and Rehabilitative Services (OSERS) which includes the Office of Special Education Programs (OSEP) and the National Institute on Disability and Rehabilitation Research (NIDRR); the Office of Human Development Services (OHDS) which includes the Administration for Children, Youth and Families (ACYF) representing Project Head Start and the Children's Bureau, and the Administration on Developmental Disabilities (ADD); and the Division of Maternal and Child Health (MCH).

Other Federal agencies which provide or will provide services for young children with handicaps or who are developmentally delayed or at-risk and their families may be included following the establishment of the Federal Interagency Coordinating Council.

Section 682 of the Education of the Handicapped Amendments of 1986 requires the establishment of a State Interagency Coordinating Council in each participating State. Its membership is to include "members representing each of the appropriate agencies involved in the provision of or payment for early intervention services to handicapped infants and toddlers and their families and others selected by the Governor."

The Federal Interagency Coordinating Council will mirror the role the Congress has stipulated for the State Interagency Councils, complementing and supporting their efforts.

The Federal Interagency Coordinating Council shall (1) provide assistance to the agency with responsibility to administer P.L. 99-457 and its implementation by the States by identifying sources of fiscal support and other resources developed by or known to member agencies. The Federal Interagency Coordinating Council shall (2) foster the development of working cooperative agreements, such as the Intra-Agency Agreement between the Head Start Bureau and Maternal and Child Health for fiscal years 1987 through 1989. This memorandum of understanding will also foster the updating of existing agreements, such as the 1978 agreement between OSERS' predecessor and ACYF's predecessor which designated liaisons between the State Education Agencies and Project Head Start, and (3) provide timely information on opportunities to compete for Federal funds in areas related to early intervention and confer concerning funding priorities.

The Federal Interagency Coordinating Council will meet at least quarterly to develop specific action steps which promote a coordinated, interagency approach to sharing information and resources in the following areas.

I. Regulation, Program Guidance, and Priorities
II. Parent Participation
III. Identification of Children
IV. Materials and Resources
V. Training and Technical Assistance

The Federal Interagency Coordinating Council will issue guidance on these areas to programs and agencies funded by the members' respective Federal offices. The Council shall be chaired by the Assistant Secretary for Special Education.

We agree that specific strategies for promoting cooperative efforts in the implementation of P.L. 99-457 will be addressed in a national interagency conference to be held in the spring of 1988.

The Council may prepare a budget request for such activities as sponsoring early intervention conferences on interagency coordination and the dissemination of information.

On behalf of the children and families for whom P.L. 99-457 was passed, we pledge our commitment to the mobilization of all available resources to assure appropriate services for this nation's handicapped preschoolers and their families.

This memorandum of understanding will become effective upon the signatures of the approving officials of the respective Federal offices and will be updated annually.

Madeleine Will
Assistant Secretary
Office of Special Education and
Rehabilitative Services
U.S. Department of Education

OCT 6 1987
Date

Dodie Livingston
Commissioner
Administration for Children
Youth and Families
U.S. Department of Health and Human
Services

10 - 2 - 87
Date

Vince L. Hutchins
Division of Maternal and Child Health
U.S. Department of Health and Human
Services

10-2-87
Date

Lucy Biggs
Commissioner
Administration on Developmental
Disabilities
U.S. Department of Health and Human
Services

10 - 2 - 87
Date

Phillip N. Hawkes
Acting Assistant Secretary
Office of Human Development Services
U.S. Department of Health and Human
Services

10 - 2 - 87
Date

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